

empower

Real People, Real Progress

Issue 9 | Spring 2012

Sibling Initiatives to Take Off in 2012

2012 will be an exciting year for siblings at The Arc, as we kick off a new partnership with the national Sibling Leadership Network (SLN), and launch The Arc's National Sibling Council.

The leadership and active involvement of siblings is critical to ensuring the full inclusion and participation of their loved ones in all aspects of life. These exciting new initiatives connect siblings as an important segment of the disability movement impacting policy, service delivery, and the quality of life for millions of Americans with intellectual and developmental disabilities (I/DD). On the flip side, this new project will provide support to siblings looking for resources and answers to questions unique to their families.

"Being a sibling of a person with

I/DD is interesting, funny, frustrating, proud, challenging, loving and respectful. Growing up with my sister Martha, I could usually convince my parents to let her try something they were worried that she could not do by telling them that I would do it with her. How amazing it would have been to hear another sibling's stories - to learn how to manage something differently, to share anger, to boast of an achievement that to my friends might seem trivial, but another sibling 'knows' the triumph," said Nancy Webster, Vice President of the National Board of The Arc and a sibling of a sister with I/DD.

Under a new partnership with SLN, an organization dedicated to providing siblings with the information, support and tools needed to advocate for their

brothers and sisters, we'll develop unique programming for siblings at The Arc's National Convention and other events, including distance learning programs on sibling issues. We'll create networking opportunities, support the development of sibling services at state



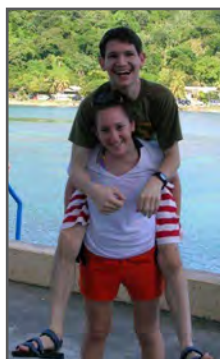
Alyssa & Bailey

Alyssa Brandt, six years old and from Springfield, Virginia, says of her sister Bailey: "I want everyone to know it is very special to have a sister like Bailey. She never gets mad or fights with me. She loves for me to sit near her and she smiles, laughs and touches me, so I know she loves me.

"Sometimes I think my friends might be sad because they don't have a sister like Bailey. Sometimes they may be a little uncomfortable because they do not understand Bailey or know how to talk to her or play with her. I would like to meet other kids who have a sister or brother like Bailey." ■



Martha and Nancy



Shira and Jeremy

Make Your Mark This Election Year

Attend the 2012 Disability Policy Seminar

Join hundreds of advocates from across the country in Washington, D.C. this spring at the Disability Policy Seminar to make your mark and make sure your voice is heard as we head into the 2012 campaign season. Learn more about and discuss the hottest topics in disability public policy and take advantage of your biggest and best opportunity to advance the grassroots agenda of the movement for people with I/DD. But this year it is even more important to make your mark and have your voice heard as we approach a pivotal presidential election in November. Together we have the power to change the political discourse and the Seminar is the perfect place to start.

More than 7 million Americans deal with the impact of public policy related to I/DD every day. From self-advocates to their family members and caregivers to people working for organizations serving individuals with I/DD, you are part



Disability Policy Seminar

April 23-25, 2012 | Grand Hyatt, Washington, D.C.

www.disabilitypolicyseminar.org

Hosted by: The Arc, United Cerebral Palsy (UCP), Association of University Centers on Disabilities (AUCD), American Association on Intellectual and Developmental Disabilities (AAIDD), National Association of Councils on Developmental Disabilities (NACDD), and Self-Advocates Becoming Empowered (SABE)



of a large block of voters who have the potential to change how our government views and interacts with people with disabilities. The Seminar offers you the opportunity to come together with other advocates, hear from experts on issues ranging from Medicaid and Medicare to SSI and the ABLE Act for long term care, and take the initiative to speak with your elected officials about what is important to you.

Monday and Tuesday, April 23-24, are filled with informative sessions from disability policy experts and networking opportunities including a breakfast just for siblings on Tuesday morning. Then the event culminates on Wednesday, April 25, with attendees organizing on Capitol Hill to personally meet with elected representatives and make a case for their cause using information about the issues provided during the Seminar. You can also attend a special webinar hosted by the Association of University Centers on Disabilities (AUCD) on March 28 to help prepare you to make the most of the event with an overview and orientation for the Seminar (visit www.aucd.org for webinar registration and details).

Register and book your room today at the Grand Hyatt in downtown Washington, D.C. at www.disabilitypolicyseminar.org for a special early registration rate. Many speakers and events are not confirmed until just before the Seminar because we want to be able to bring the most updated information on the hottest topics to the table. But, you can register now – special rates on rooms end March 20. ■

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Mission Statement

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

March is Developmental Disabilities Awareness Month

March is Developmental Disabilities Awareness Month, giving individuals with intellectual and developmental disabilities (I/DD), their families and advocates the ideal platform for raising the public's consciousness about I/DD. Let's take advantage of this time during a crucial election year to make some noise! March is the perfect time to bring national attention to our cause by speaking out, speaking up and showing everyone that "We've Got the Power!" (check out the article about our 2012 voter engagement campaign below).

And we do have the power – the power to make a difference, improve a life and change the way our society views people with I/DD. Although your advocacy and the activities of organizations like The Arc have led to many positive changes over the years fostering respect, inclusion and full participation for people with I/DD, there are still instances in which people with I/DD and their families are not

receiving the support and services they need to fully function as valued members of their communities or to achieve their fullest potential. If you're reading *Empower*, we know you care – now, here's what you can do to educate and motivate your colleagues, friends and neighbors, elected representatives (or even a stranger) about Developmental Disability Awareness Month and our movement.

- Connect with your local Chapter of The Arc to find out if they have any Developmental Disabilities Awareness Month events which you can get involved in. You can find your local chapter's contact information by visiting www.thearc.org and clicking on "Find a Chapter" at the top of the page.
- Tell your story. If you have a blog or are active on social media, announce Developmental Disabilities Awareness month to your followers and friends starting March 1 and tell them why you advocate for people with I/DD.

Or visit The Arc's blog, Facebook page or Twitter profile and tell us why Developmental Disabilities Awareness Month matters. You can find our blog and links to all of our social media channels on our home page at www.thearc.org. We'll be posting more about Developmental Disabilities Awareness Month in March.

- Write a letter to the editor of your local newspaper telling them that it is Developmental Disabilities Awareness Month and asking for their help in raising the public's awareness of I/DD. Mention that millions of Americans and their families live with I/DD (many in your own community), share your own story or urge people to find out more about The Arc and the work we do. Our website is a valuable resource for information about diagnoses, public policy and programs vital to people with I/DD and their families. ■

Who's Got The Power? The Arc's Advocates Have The Power!

Did you know that in 2008, only 46% of people with intellectual and developmental disabilities (I/DD) who were eligible to vote actually did so? That's compared to 64% of people without a disability! You have the power to create change, but staying home from the polls won't impact any of the issues important to people with I/DD – we need YOU!

To prepare for the 2012 elections, The Arc is launching a nationwide campaign called "We've Got The Power!" to engage chapters and allies to register, educate and mobilize people with I/DD to vote in 2012. By promoting civic engagement, The Arc will be more effective in putting the issues of people with I/DD on the agenda of all candidates for public office. When more people with I/DD participate in the democratic process, we increase our power to fight for real participation in society and independence – so get involved!



Through online trainings, downloadable, easy-to-use materials, links to voter registration information and other capacity-building efforts, The Arc's aim is to ensure that our members have the tools necessary to engage in the political process as individual voters. And we will support our chapters to develop solid skills in working with other community groups to educate candidates and the greater community about why issues important to people with I/DD and their

Introducing William Washington

Support The Arc's Work to Employ People with Disabilities

At The Arc's headquarters, the first thing you see when you walk in the door is William's smile. As chief receptionist, William Washington does so much more than just answer phones and greet visitors at the national office. William is the heart of the operation and proof that nationally we work to reflect The Arc's core values and take seriously the need to showcase full participation and independence for individuals with intellectual and developmental disabilities (I/DD) in their community.

Like many other individuals with I/DD who work full time, it has been a journey for William to find the right job. His employment experience began when he was just 16, and he started working with The Arc of the District of Columbia in 1998. Over the years, William, who is now in his fifties, gained the skills he needed to enter the community in a competitive job with competitive wages.

With the help of his Job Coach, Pat Norman, William continues to grow in his role with The Arc and become more independent. He now travels to work alone (in a handi-van) four days a week, and Pat accompanies him once a week. Always willing to assist any of his co-workers, he is an indispensable part of The Arc's staff. The desired outcome for William is to function without the support of his coach, receiving natural supports within the workplace, fully included as an independent competitive worker.

While the national office of The Arc is known for its public policy and advocacy work, we also lead national initiatives that challenge employers across the nation to commit to employing people like William in their community. **The Arc needs support from people like you to ensure that progress con-**



"I like to come to work independently on my own, having a job and helping myself. My family is most important and I can help them out with my job and work." - William Washington

tinues across the country, leading to meaningful employment for people with I/DD. Take the opportunity to support William and future employees with I/DD by making a donation today with the envelope provided in this edition.

The Arc has also provided a number of opportunities for William, including the chance to travel. Before joining the national staff, William had never been on an airplane. His work has allowed him to travel to New Mexico, Pennsylvania, and Florida for The Arc's annual conventions. Additionally, William has visited the U.S. Capitol for events, and had the opportunity to visit the White House on a number of occasions, including the signing of Rosa's Law.

"I like coming to work every day because I like my job. I come to work and I answer the phone, I take messages and transfer them to other colleagues in the office, I greet people coming to the office, and I do what my colleagues ask me to. I like to work with everyone in the office," says William.

If you or someone you know would like help finding community employment opportunities there are a number of local resources that can help:

- Contact your state or local I/DD agency or State Vocational Rehabilitation Agency for information about employment services for people with disabilities in your area. To find your State Vocational Rehabilitation Agency visit <https://askjan.org/cgi-win/Type-Query.exe?902>.
- If you are a student age 16 or older who receives special education services, your Individualized Education Program, or IEP, should include a transition plan that includes goals for your transition from school to adult life, including employment. While you are still in school, you should be learning the things you'll need to find a job or continue your education after you graduate. For some students, the transition plan may include accessing services through the state Vocational Rehabilitation Agency.
- Contact your local chapter of The Arc. They can assist you in finding out what you need to do and who to contact in your area. You can find your local chapter's contact information by visiting www.thearc.org and clicking on Find a Chapter at the top of the page.

And, we hope that if you attend The Arc's National Convention in Washington, DC this October, you'll look for William (and his smile) and say hello! ■

Rob's Story – Unique but Similar to So Many The Arc Represents

When you're pregnant, the best drink is no drink at all.

Sound advice – and common sense, right? Well, this slogan is actually on a bumper sticker created by Rob Wybrecht, the first infant diagnosed with Fetal Alcohol Syndrome (FAS) in 1973. This diagnosis at birth has been extremely helpful to both Rob and his parents, who adopted him at 11 months old, allowing them to think differently so that Rob can achieve in life.

The damage of Fetal Alcohol Spectrum Disorder (FASDs) caused by a mother's drinking during pregnancy is irrevocable. Effects could include physical, mental, behavioral, and learning difficulties, and intellectual and developmental disabilities (I/DD) with possible lifelong implications. Each year in the United States, as many as 40,000 babies are born with FASDs. According to the federal government, the cost to the nation for FASDs alone is about \$6 billion a year.

However, with early identification and diagnosis, children with a FASD can receive services to maximize their potential and achieve their dreams. They can benefit from early intervention services and an Individualized Education Program in school that includes preparation for transition from school to work and possible further education. And many people with FASDs benefit from one-on-one counseling support.

When Rob was in 7th grade, he came home after school very excited about a quote he just heard and told his mother, "Mom, that is how I learn!" The quote was: *Tell me, I will forget. Show me, I may remember. Involve me, I will understand.*

Rob excelled in the culinary arts in high school, leading him to work in a restaurant which he enjoyed for many years. But changes in management led to challenges for Rob, which could have been solved with the help of a job coach – but Rob's access to this service had ended given his success in the position. So Rob moved on, and found ways to make his next job as a church janitor work, with the help of checklists to help him stay on task. He currently works as office support staff with The Arc of Kent County in Michigan and travels both nationally and internationally speaking to others about how FAS affects his life, and about one area of advocacy he is especially passionate about - employment and job coaching. Most recently, he spoke at the First European FASD Conference in 2010 in the Netherlands and will speak at the next one in Barcelona, Spain in October.

Now 39 years old, Rob is a Project Coordinator for the Self-Advocates with FASD in Action, or The SAFA Network. (Learn more at <http://www.thearc.org/page.aspx?pid=2440>) The Arc, together with the Substance Abuse and Mental Health Services Administration (SAMHSA) Fetal Alcohol Spectrum



Rob Wybrecht with his mother Barbara (left) and The Arc's Leigh Ann Davis (center) selling FASD prevention awareness bumper stickers at a conference.

Disorders (FASD) Center for Excellence, hired Rob to help guide and support The SAFA Network. This project is creating a strong network of self-advocates with FASDs who can provide leadership in promoting and organizing self-advocacy efforts in their own backyards and nationwide. Rob assists the SAFA Network by providing outreach to individuals with FASDs through conference calls, face-to-face meetings with the SAFA Network, and presentations and exhibits at regional and national conferences throughout the country.

Rob is a shining example of what is possible for people with FASDs. With continual support and encouragement from his parents, Ted and Barbara Wybrecht, and other support people throughout his life, Rob continues to raise the bar for his own personal life goals and in advocating for others to reach theirs. What a shining example of what can happen when people with intellectual and developmental disabilities (including FASDs) are encouraged to reach for the stars!

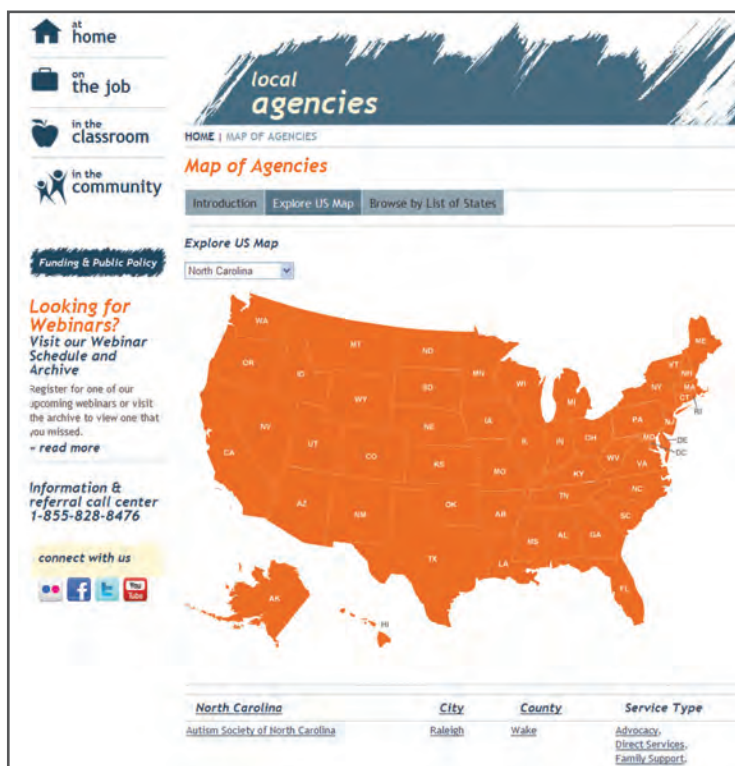
The Arc is here to help people of all diagnoses, including FASD. Learn more at www.thearc.org. ■

News from the Autism NOW Center

In 2011, The Arc launched the Autism NOW Center – the National Autism Resource and Information Center – to help people searching the web separate fact from fiction when it comes to autism.

Led by The Arc's National Initiatives department, and funded by the Administration on Developmental Disabilities, 2011 was a busy year for the Autism NOW Center. With five regional summits, dozens of webinars, and the creation of a top-notch informational website with input from partners in the disability field, we went into 2012 with exciting ideas to expand upon that important work. While www.autismnow.org is becoming a go-to resource for families, individuals with autism, and experts in the field, we decided it was time to go mobile, and map it!

The center's staff rolled out two exciting new features on the site recently – a mobile version, allowing users on mobile devices like smart phones and tablets to see an optimized version of the site, and a local agencies directory in the form



of a map. This mobile version lets users get to content faster on the go, and creates better accessibility overall for the site. The local agencies directory provides an easy-to-use way to find agencies in your state that can help with services, support and resources for living with autism and other developmental disabilities.

To view the mobile version, simply visit the site (www.autismnow.org) on a smart phone or tablet – like an iPhone or iPad. To view the Local Agencies Directory, visit www.autismnow.org/map.

The new features of the site are only the beginning in what will be a busy year

for the Autism NOW Center staff. Other planned features include commenting on blog articles, a message board, an enhanced community calendar and new video content.

Did you know you can get involved with the Autism NOW Center right now? Learn how at www.autismnow.org/participate. ■

siblings continued from page 1

and local chapters of The Arc, and work to establish state and local chapters of the SLN.

Born out of this partnership is The Arc's National Sibling Council. The Council will offer opportunities for networking and support to siblings and their families, build a broad network supporting the advocacy and programmatic efforts of The Arc, offer leadership development and training, and offer opportunities for siblings to connect in a variety of ways. In addition, The Council will be a place that siblings can turn to when they need guidance or support in situations unique to their family and their role as a sibling.

Shira Jacobson, a 25 year old sibling of Jeremy Jacobson, says: "My greatest challenge as Jeremy's sister has almost always been how to be his younger sister. The challenge for me was that as I went through my teenage years and beyond, I kept growing up and passing typical milestones that Jeremy might not hit. I had to learn how to help support him without making him feel like I was trying to take the place of the older sibling in the relationship.

She added: "I think that there is a lot of pressure that we as siblings often put on ourselves to be an alternative parent figure, a friend, a case manager, and a sibling all at the same time and it doesn't always help...and often hurts.

It will be helpful to speak with others on The Arc's Sibling Council to guide each other through these situations."

The Arc's National Sibling Council welcomes all siblings and those who support siblings who are members of The Arc either at the local, state or national level. Those interested in becoming Council Contributors and supporting the work of this new initiative directly may donate online to ensure the establishment and sustainability of this essential new program. Visit www.thearc.org and click on the "I Am a Sibling" link. And, to get involved with the program, please Contact Laurie Ertz, Director of Chapter Excellence, ertz@thearc.org. ■

Apostrophe Magazine Cancels "Can't"

Can't and shouldn't.

Too often those words turn into "could have" and "should have" — regrets about lost opportunities. *Apostrophe* magazine helps turn "can't" and "shouldn't" into "can" and "should."

The name comes from a song by the late rocker Frank Zappa about a man talking to his dog. We all can relate to that, but in Zappa's song, the dog talks back.

"You can't say that!" the man tells the dog in disbelief. "I do it all the time," the dog replies. He talks, he says, even with all the apostrophes thrown his way: can't, won't, don't and shouldn't.

People with disabilities face the same apostrophes. Too often they're told what they can't do. *Apostrophe* magazine emphasizes what they can do.

Every issue features stories about people living productive lives and achieving success at home, at work and at play.

Lissie Clark, a 34-year old businesswoman from Great Falls, MT, is a good example. Lissie has overcome Fetal Alcohol Spectrum Disorder (FASD) and other obstacles to start a successful business. Today, she operates Lissie's Luv Yums, baking and selling all-natural dog biscuits to customers across the United States. At the same time, Lissie uses her business to educate people about the dangers of alcohol consumption when you're pregnant.

Apostrophe also gives readers practical information they can use every day.

A staple of the magazine are how-to features. In past issues they've explained, using words, graphics and photos, how to make a hearty clam chowder, how to paint a room and clean up afterward, how to plant a vegetable garden, how to build a birdhouse, how to shop wisely for gro-



ceries, how to file a tax return, and how (and where) to vote.

In "It's the Law," Disability Rights lawyers have written about

guardianship, end of life issues and the Olmstead Decision.

They tell their readers about websites worth visiting and books worth reading. A recent issue included a review of The Everyday Guide to Special Education Law and the companion workbook.

Every issue includes a column by a writer from People First. Contributors have explained to *Apostrophe* readers the marriage penalty, self-advocacy and the campaign to end the use of the "R" word.

The Winter 2012 issue introduces

"Jigsaw," a cartoon strip created by Tess Langston, a young woman with autism.

Like The Arc, *Apostrophe* believes in promoting and protecting the human rights of people with intellectual and developmental disabilities and supporting their full inclusion and participation in the community as long as they live. They share The Arc's core values of people first, equity, community, self-determination and diversity.

They believe the power of the pen (and the camera) can help make that philosophy a reality.

Their stories and photos show people achieving independence, contributing to their communities and enjoying life. They emphasize human dignity and take pains to use people first language. Welcome to the world of "Can" and "Do." ■



The Arc has launched a new relationship with *Apostrophe Magazine* to bring our members a valuable new resource and a refreshing perspective on what a publication for people with disabilities should be. In 2012, you'll find guest columns from The Arc's staff about topics important to you in the pages of *Apostrophe* and on their blog (www.apostrophemagazine.blogspot.com) and you'll frequently see interesting news and information from the publishers of *Apostrophe* in *Empower*, our E-newsletter and on our blog. Check out their latest issue and get subscription information at www.apostrophemagazine.com ■

advocates continued from page 3

families impact every American—and why candidates who support our issues should be supported as well. Arm yourself with the knowledge and skills necessary to make some noise on the campaign trail!

We have already started promoting the "We've Got The Power!" message online and during the 2011 National Convention. We will continue to make this an integral component of our advocacy work and strive to improve voter participation in the I/DD community. So harness your Power in your community by getting involved now!

To learn more about the "We've Got The Power!" campaign, contact Dee Dee Eberle, Director of Chapter Organizing & Advocacy at eberle@thearc.org or 202-534-3700. ■



*For people with intellectual
and developmental disabilities*

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inside:

*Sibling Initiatives to
Take Off in 2012*

*Make Your Mark This
Election Year*

*Developmental
Disabilities Awareness
Month*

*Who's Got The Power?
The Arc's Advocates*

*Introducing William
Washington*

*Rob's Story – Unique
but Similar to So Many
The Arc Represents*

*News from the Autism
NOW Center*

*Apostrophe Magazine
Cancels "Can't"*

Save the Date:

The Arc's 2012 National Convention:

Achieving Inclusion


The Arc

**Inclusion
international** 



In conjunction with Inclusion International

October 25-28 in Washington, D.C.

Don't miss the single most important gathering of the I/DD community before the 2012 election! Find out more at www.thearc.org